DOCUMENT RESUME

ED 412 684 EC 305 882

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TITLE Implementing Self-Determination Initiatives: Some Notes on Complex Change.
INSTITUTION Responsive Systems Associates, Lithonia, GA.; Minnesota Univ., Minneapolis. Inst. on Community Integration.; Syracuse Univ., NY. Center on Human Policy.
SPONS AGENCY National Inst. on Disability and Rehabilitation Research (ED/OSERS), Washington, DC.
PUB DATE 1997-00-00
NOTE 41p.
CONTRACT H133B30072
PUB TYPE Opinion Papers (120)
EDRS PRICE MF01/PC02 Plus Postage.
DESCRIPTORS Change Strategies; *Delivery Systems; Demonstration Programs; *Developmental Disabilities; Innovation; Models; Personal Autonomy; Program Administration; Program Development; Program Proposals; Resource Allocation; *Self Determination; State Programs; *Systems Analysis

ABSTRACT

This paper presents thoughts resulting from review of proposals by state developmental disabilities authorities, submitted to the Robert Wood Johnson Foundation, that were designs for change initiatives in self-determination systems. These reflections on the use of service money and the provision of supports to people with developmental disabilities are organized into several logic diagrams on which the proposals appear to be based, all of which suggest the limits and contradictions involved in implementing the concept of self-determination. One approach sees self-determination as an agreement between the individual (who agrees to certain responsibilities) and the administrative service system (which agrees to corresponding services). A second logic diagram sees the initiative in terms of six interacting core processes, four of which are managed directly by the service system and two influenced by, but outside of, the direct control of service workers and agency managers by the initiative's values. A third logic diagram shows self-determination as a solution to a variety of service system problems related either to providing services for people with developmental disabilities or to making the best use of public funds. The next logic diagram focuses on outcomes, either increased consumer satisfaction or better use of public funds. Other issues addressed include the expanding service capacity and use of natural supports to replace paid services. Finally, several models of overall project design are discerned in the proposals. (DB)

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Implementing Self-Determination Initiatives

Some Notes on Complex Change

John O'Brien

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Preparation of this paper was partially supported through a subcontract to Responsive Systems Associates from the Center on Human Policy, Syracuse University for the Research and Training Center on Community Living. The Research and Training Center on Community Living is supported through a cooperative agreement (number H133B30072) between the National Institute on Disability & Rehabilitation Research (NIDRR) and the University of Minnesota Institute on Community Integration. Members of the Center are encouraged to express their opinions; these do not necessarily represent the official position of NIDRR.

Preparing for a hundred battles

In response to the Robert Wood Johnson Foundation's request for proposals for self-determination systems change initiatives, a three-fourths majority of states want to make significant change in the use of service money and the provision of supports to people with developmental disabilities. In the rapidly expanding discussions about managed care, long term care reform, and, now, self-determination, I feel even more than usual sympathy with Winnie-the-Pooh's description of himself as "a bear of very little brain." To try to catch up, I have imagined some of the issues and conflicts that might play themselves out as systems move from the optimistic language of proposal writing into the more uncertain work of making deep change in the power people with developmental disabilities and their families have in relationship to service providers, regulators, and system administrators.

These notes are based on my reading of a description of self determination (Nerney & Shumway, 1996) and a review of 10 of the 38 proposals submitted to RWJ in the summer of 1996. I considered reformer's understanding of the concept of self-determination, the kinds of changes they identify as necessary to achieve it, and their choice of methods for making change. I then abstracted several simple logic diagrams from my understanding of these proposals read and re-read as a group. Each of these logic diagrams provides the basis for reflection on some of the apparent conditions for project success and some of the limits and contradictions in implementing the concept of self determination as the proposals define it.

Looking at the initiative in this way might seem like a lack of enthusiasm for it. That is not my sense at all. I think that the self-determination initiative is important and timely, with real potential to benefit people with disabilities and their families by combining and extending several important reform efforts in a way that has a good chance to keep attracting and organizing support. What I am doing here is struggling for understanding by identifying some of the contradictions, limits, and reasonable opposition that the people who implement the several projects might encounter.

My comments are not based on any insight into the politics or microeconomics of managed care (see above, under "bear of very little brain"). Instead, they are based on what I have learned from people with experience in doing a number of the core processes defined by the proposals - converting agency service patterns; making and administering individual budgets based on person centered plans; assisting people in ways that respect and expand their choices; aligning the contributions of

family, friends, and community members; and supporting people to establish their own homes and ways to contribute to their communities.

It is entirely possible that the lessons from these smaller scale experiences have limited relevance to this initiative. The particular combination and emphasis contributed by the organizing idea of self-determination creates interactions among these processes that could accelerate their combined effects. Adding the system's formal authority might dissolve problems that have been difficult to overcome in efforts that have developed in the system's margins (though I confess to skepticism about this). In a broader sense, the pace and extent of more than a generation of rapid change in the ways we see and support people may by now be sufficient to radically shift the context in which we all work in ways that will allow a deep and rapid transformation to a system that encourages and supports self-determination. Such historic moments might come, and this could be one of them. In case my questions and quibbles turn out to be obsessive and overly pessimistic, I will be happily surprised.

In the meantime, it seems reasonable to expect both opposition and difficulties arising from the contradictions within the initiative. As we begin to implement this bold reform, prudence reminds us of the advice of the great strategist, Master Sun Tzu:

> *If you know your opponent*
> *and you know yourself,*
> *you need not fear the result*
> *of a hundred battles.*

I imagine that those who want to implement significant change in the system described by the groups of reformers who authored the proposals will need to engage in more than a hundred battles. Summarized succinctly, the proposals portray a system addicted to benevolent professional-bureaucratic control of the lives and futures of people with developmental disabilities and enmeshed in a welter of policies and habits of practice in which marginal breakthroughs in supports that promote community inclusion contrast sharply with a central tendency to service people in ways that segregate them in small groups as they house and occupy them. If stopping to think about, and argue with, the issues raised here will sharpen their foresight, elaborate their strategic understanding, and strengthen their resolve even a little bit, I will be glad.

Managing the appeal of self-determination

The RWJ initiative is addressed to state developmental disabilities authorities and calls for commitment to system's change. Though the foundation's high status and willingness to invest in state agencies increasingly strapped for cash goes a ways toward explaining why 38 groups mobilized a response to the request for proposals, several features of self-determination as the initiative defines it contribute to its appeal. Self-determination...

...offers a solution to a set of knotty problems, such as responding to people on waiting lists. The effectiveness of the solution is underwritten by the widely public success of an RWJ funded project in Keene, NH

... provides a way to mobilize and direct the efforts of people who want to improve services and provides a way to piece together a variety of state level change efforts and carry them forward

...presents itself as a practical way to realize values widely espoused in the developmental disabilities field such as choice, person-centeredness, responsible community participation, and cost control

...remains ambiguous enough to allow people with many different agenda's to buy in

...fits the form and scope of the state systems change projects which have become familiar through such federally funded initiatives as CSLA, supported employment systems change, and transition from school to work; in this sense it is a bureaucratically familiar way to support a focused effort for change

...appears to provide leverage for real steps forward within the existing (changing) federal-state medical assistance program and within state structures and current state government reforms; in this sense the project promises substantial -even radical- change in the efficiency and effectiveness of services without calling for fundamental change in Medicaid or in whatever administrative arrangements are current or proposed in the states.

...allows state officials to make strong statements about significant changes while they delegate most of the responsibility for actually making the changes to people with disabilities and their families, local service coordinators, service providers, and sub-state authorities such as county or regional administrative bodies. This moves state authorities into the admirable position tagged "steering not rowing" by the government re-engineers who remain busy in state capitols.

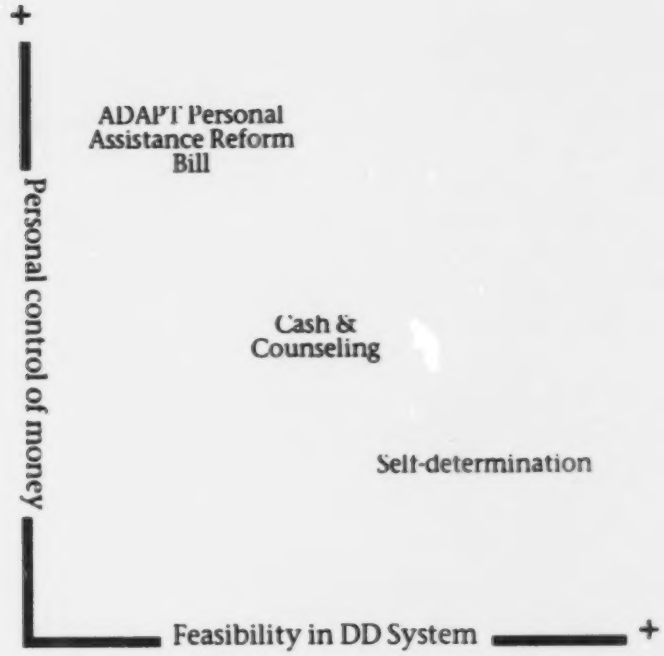
These seven characteristics of self determination are considerable

strengths from the point of view of making change within state bureaucracies. They make the initiative feasible, and thus attractive. They also, and appropriately, leave most of the learning to be done later, primarily through local and personal action. These notes consider the self-determination initiative from the perspective of such local action.

Effective state leaders will remember the difficulty of the assignment the project gives pilot areas and they will be alert to owning and working to change the many ways the policies, practices, and culture of the state system promote the status quo. Without such active awareness, a sensible way to promote learning through local pilots will feel to local learners like they have caught a hot potato.

Experience in the many ways large systems resist change suggests that no matter how committed state level leaders are to straightening the way for self determination, their system will not be able to restrain itself from gumming up the initiative' progress. Almost certainly the pilot efforts will get stuck in the flypaper of details around accounting, contracting, licensing and inter-governmental relations. Most proposals identify a state level person associated with the project. States that remember the stickiness under the surface appearance of feasibility will fill this role with a "fixer": a credible person with strong informal connections throughout the state bureaucracy who has the clout to move the nuts and bolts agenda defined by local pilots.

Dealing with some disappointment among strong supporters could challenge the initiative. Brief, ad hoc investigations of the meaning groups of people enthusiastic about system change converge on a common sense understanding of what self determination means. Two groups of self-advocacy leaders and two groups of parent advocates I have met with for other purposes in the past few weeks are excited that their state wants to implement self-determination because they agree that it means: "The person (or the family) gets the money." However sensible this policy might be, it is clearly not what "self-determination" means in the context of these proposals which can be contrasted with two other widely discussed approaches to reforming service funding. To get a sense of this initiative's relatively conservative trade off of personal control for feasibility, compare this initiative with ADAPT's proposal to create a non-medical entitlement to self-directed attendant care and with the cash and counseling initiatives being tested in several states.



Self-determination from the point of view of people with developmental disabilities

Sometimes proposals talk about self-determination as an opportunity: the person will have choices about who provides what service and when. Sometimes they talk about self-determination as a competency to be acquired: the person will participate in training delivered according to a self-determination curriculum devised by experts. Overall, though, proposals say much less about self-determination from the point of view of people with developmental disabilities and their families than they say about the administrative processes (e.g. individual budgeting) which define self-determination as an offer the service system makes them.

Proposals differ, but one plain language summary of the self-determination offer looks like this. Those projects that don't recognize this offer may find it helpful to make their own summary in a similar form.

If you agree to...	then	we agree to...
...learn about how to take part in the allocation process & how you can use the money we give you		... train you about how self-determination works & what your responsibilities are
...learn about what is possible for you		...help you make a plan & ask people & other funders for help and money
...make a plan describing the future you desire & specifying the supports you need to pursue that future		...give you a fair share of the money we have to implement your plan
...seek help from your family, friends, and other community members that will reduce the cost of your services		...keep some money in reserve so we can help you pay for more supports if things change & you need them
...seek to maximize other sources of money available to you (e.g. housing benefits)		...give you a choice about what assistance you need, when you get it, and who provides it
...seek to find work & contribute some of your income toward the cost of services		...buy the supports that you can afford in such a way that - providers only get paid for the services you get -your service providers know that you are the customer & your satisfaction matters
...accept the amount of money negotiated in the allocation process		...work hard to make it possible for us to buy anything that makes sense in terms of your individual plan by working for changes in local, state, & federal rules
...be careful and efficient in what you buy with the money		

Given the constraints imposed by the regulations and service practices that the initiative itself is designed to overcome, it might be said that people with disabilities are being given a chance to participate in a political and social experiment designed to discover how much flexibility and personalized support it is possible to wring out of a hybrid

medical system that concurrently, and as a whole, is the object of attempts to control its costs by others who are higher in state and federal bureaucracies. Pilot administrators who want to build momentum will be audacious in the level of flexibility that they claim and give away up-front.

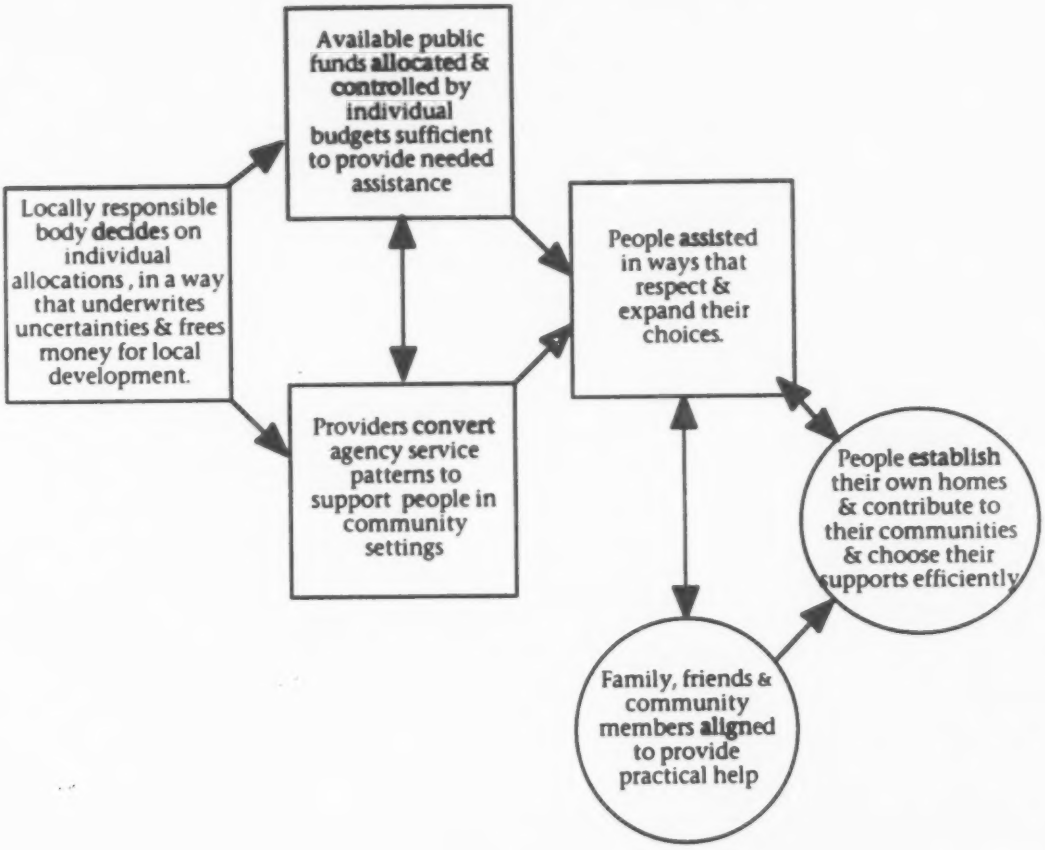
While most proposals call people "consumers", the offer they make demands a bit more than a trip to Nordstroms does. In exchange for greater choice, people and their families and friends are asked to assume an increased share of the work and risk that has been assumed by service providers for those people in 24 hour services This could seem a little like the airline's effort to cut the cost of baggage handling by training travelers to carry their own bags. This self-help initiative has proven so successful that the industry can redefine carry-on space as a feature to advertise proudly and carry-on as a privilege that they now regulate.

In the proposals, self-determination is most often used in sentences about how services happen. This contrasts with a common usage among disabled activists and their allies that uses self-determination as meaning being in control of your life. Maybe proposals' references to "person-centered-planning" are intended to provide that context to discussions about individual budgets and consumer satisfaction. This, however, is probably not enough. There is a depressing number of demonstrations that earnest effort can be expended on person-centered plans that do no more than specify minute changes in staff routines.

The proposals don't specify which of the terms of this offer are negotiable or how negotiations might proceed. Most proposals take either a whole system or a local authority as their unit of change and aren't specific about whether or how a person might decline the offer to be self-determined as it is defined by the service system.

The logic of the initiative in terms of core processes

The initiative can be described in terms of six core processes, four of which are managed directly by the service system (the boxes in the diagram) and two of which (the circles) are influenced by the other four, but placed outside the direct control of service workers and agency managers by the initiative's values.


Available public funds allocated & controlled by individual budgets sufficient to provide needed assistance
Locally responsible body decides on individual allocations, in a way that underwrites uncertainties & frees money for local development.
People assisted in ways that respect & expand their choices.
Providers convert agency service patterns to support people in community settings
People establish their own homes & contribute to their communities & choose their supports efficiently
Family, friends & community members aligned to provide practical help

From the perspective of its process, the initiative's logic can be stated like this:

People with disabilities will have the best possible chance to establish and maintain their own homes, contribute to their communities

through participation in paid work and civic activity, and make efficient and effective choices about the supports they consume

if

Family members, friends, and community members assume responsibility to align their efforts and resources in ways that offer the person practical help with cash value. Part of this help includes influencing the way necessary assistance is offered.

and if

People receive required assistance in ways that respect and extend their range of options and choices. Part of this assistance includes offering necessary help to convene family, friends, and community members, and responding to their influence.

Assistance is most likely to respect and extend people's options and choices

if

Available public funds are allocated and controlled by individual budgets which are sufficient to provide necessary assistance and responsive to individual choices.

and if

Both the selection of service providers and disbursements to them are controlled by the person using services or their family so as to allow the emergence of a market in supports.

and if

The process of establishing and expending individual budgets induces providers to use available technical assistance to convert inefficient or ineffective service investments into appropriate supports or stimulates development of new providers, including people employed specifically to assist particular individuals.

and if

Provider agencies convert existing patterns of service from a culture based on congregating and controlling people to a culture based on respecting and supporting people's choices about how they want to live and participate in community life.

Necessary changes in allocation and control mechanisms and support are most likely to happen

if

Locally responsible bodies hold the power to make allocation and rationing decisions according to locally developed criteria for

- underwriting the uncertainties arising from changing needs for individual support
- providing funds for investment in developing the necessary infrastructure to manage the local system effectively and
- serving eligible people from a locally managed waiting list.

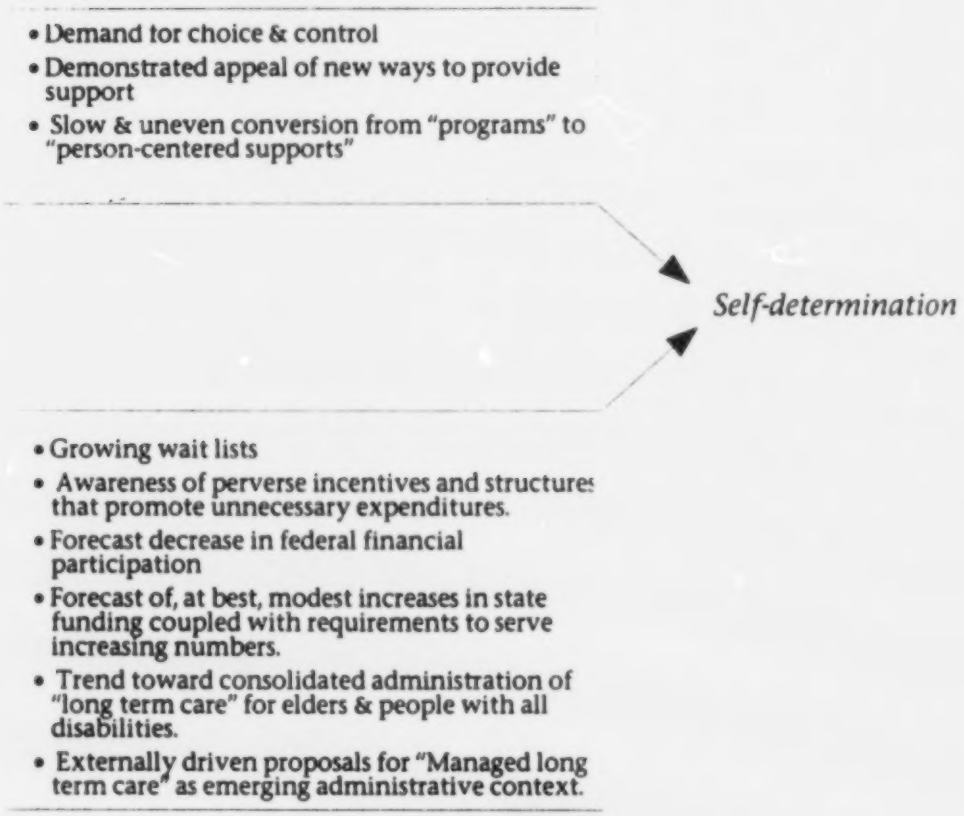
and if

State and federal authorities increase flexibility and local power by removing barriers to local individualized budgeting, redesigning quality assurance and inspection functions, and focusing data collection on accountability for costs and outcomes.

Proposals vary some their adoption of this logic, particularly around the role and power of local authorities. As soon as possible, each pilot should articulate its own logic and assumptions in order to provide an agreed base for learning.

Self-determination as a solution

Proposals present self-determination as the solution to a complex set of service system problems. One sub-set of these problems relates to the improvement of supports for people with developmental disabilities. The other relates to making best use of public funds, given a continuing shortfall and the forecast of slowed growth in public expenditure on services. These problems can be depicted as driving forces promoting interest in self-determination as a way to deal with system difficulties.


• Demand for choice & control
• Demonstrated appeal of new ways to provide support
• Slow & uneven conversion from "programs" to "person-centered supports"
Self-determination
• Growing wait lists
• Awareness of perverse incentives and structures that promote unnecessary expenditures.
• Forecast decrease in federal financial participation
• Forecast of, at best, modest increases in state funding coupled with requirements to serve increasing numbers.
• Trend toward consolidated administration of "long term care" for elders & people with all disabilities.
• Externally driven proposals for "Managed long term care" as emerging administrative context.

Proposals identify one or more of these forces that promote self-determination as reasons to improve the quality of supports through self-determination:

- A strong and increasing demand from people with developmental disabilities (a growing number of whom are members of self-advocacy groups) and their families for more choice about how they live, more control over the supports they use, and more control over the

public funds available to support them. Those who make this demand indict many current service models and practices as the biggest barriers to greater choice and control.

- The rising standard set both by talk about "person-centered supports," "outcome based management", and "continual quality improvement" and by the steady accumulation of positive results in programs like family support, supported employment, and supported living, including initiatives for home ownership.
- Frustration at the slow, uneven pace of conversion from "program-centered" to "person-centered" approaches -including the endurance of congregate and professionally controlled approaches to family support, day services, and residential services. This slow rate of change limits the number of people and families who get the assistance they need to pursue regular lives as valued, disabled members of their varied communities and creates a system with a steadily growing difference between typical services, which continue to account for the greatest share of expenditure, and new forms of support, which tend to be marginal if highly visible.

The proposals identify one and usually more of these forces that promote self-determination as reasons to adopt self-determination as a way to make the best use of available public funds:

- Waiting lists, especially waiting lists for residential services, are a chronic and increasingly visible problem. People and their families are forced into crisis as the most common path off the residential waiting list. There is little rationale for considerable differences in amounts of public expenditure between eligible people with need for similar amounts of assistance who live with 24 hour service and those who live with families beyond the unpleasantly obvious, "He got here before you, often because he went to the institution and you did not."
- Awareness that the system has grown in ways that structure in some unnecessary expenditures and create incentives that drive up costs without a corresponding rise in benefits to people with developmental disabilities. Many of these problems are associated with the costs of compliance with state and federal Medicaid regulations. Other problems arise from the way rates are set and the way funds are contracted to support places in agencies.
- A forecast that Medicaid reform will at least decrease the rate of growth of federal financial participation if it is not assumed to decrease funding from current levels. (It hard to tell which kind of decline the proposals anticipate, proposals are more likely to make

broad statements about decreasing federal funds than more specific forecasts about the nature of the decrease in the budget for people with developmental disabilities.)

- A forecast that state expenditures are unlikely to rise by much, if they rise at all, and that whatever increases may be available will either...

  ... be tied to specific groups (e.g. people moving from institutions under judicial supervision, people in crisis, or high school graduates in need of a day service), or

  ... possibly be coupled with a mandate to serve significantly more people in order to accomplish a purpose like "clearing the wait list."

- Recognition of a trend toward consolidated administration of services for elders who need support and people with all disabilities under the heading of "long term care." This may not remove distinct administrative programs for people with developmental disabilities, but it can lead to considerable decline in influence for developmental disabilities system leaders through...

  ... creation and enforcement of overall long term care policies which are likely to be strongly influenced by the agenda of the nursing home and home care industry, the lobby for elders, and the very substantial unmet need of people with other disabilities.

  ... reallocation of some of their planning, budgeting, and evaluation functions to more general "long term care" administrative units.

  ... exposure to new depths of uncertainty as the long term care system acts on it's forecasts of a level of need for long term care among elders that threatens to overwhelm both the economy's capacity to fund it and the society's capacity to supply people to provide assistance.

- A keen awareness that state Medicaid reforms create a new administrative context which imports "managed care" as a framework for reform. This ...

  ... threatens the distinct and focused status for developmental disabilities services that many states have achieved and thus decreases the influence of developmental disabilities managers and their allies in favor of elected and appointed administrative reformers with ideological certainty about their solutions. At best these reformers have little specific interest in people with developmental disabilities and at worst they see the achievements of the developmental disabilities system in supporting individuals and families as profligate.

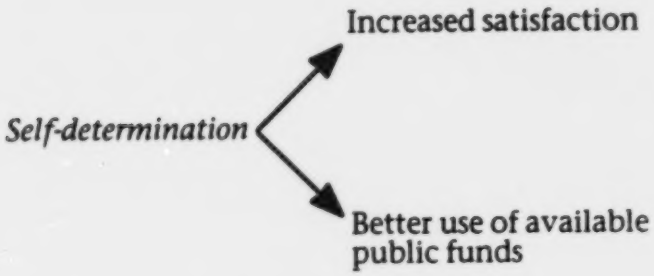
  ... introduces an unfamiliar way of thinking and a set of bureaucratic

mechanisms that have uncertain application in any part of the "long term care" field and seem to pose a special threat to the kinds of supports that have developed farthest from the medical model of care, such as family support, supported employment, and supported living.

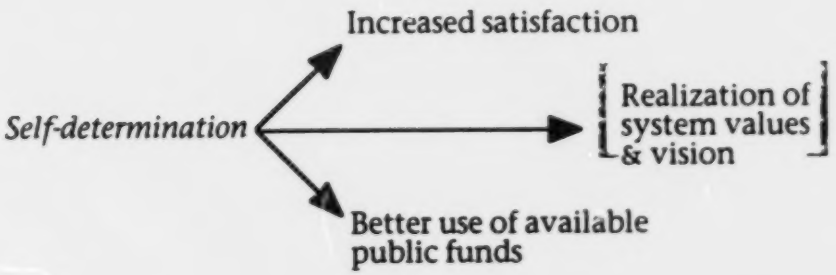
These last two forces, which have pulled many developmental disabilities system leaders into the unfamiliar and troubled waters of debate over long term care reform, make the RWJ self-determination initiative particularly timely. The status of the Foundation among health care reformers lends credibility to the developmental disabilities system agenda in debates over how state and federal governments will contain costs. The scale of Foundation funding makes significant effort for change possible. The definition of the initiative makes it a useful tool for shaping the developmental disabilities system agenda by demanding work relevant to the broader policy debate on improving the capacity to manage costs as well as work on the internal problems of paying too much for programs that don't match current notions of good practice. This double aspect of the self-determination initiative gives developmental disabilities system leaders two opportunities. It provides a way to raise some of the issues around person-centered supports while responding to state and federal process of long term care reform, and it offers a way to add urgency to the process of changing existing developmental disabilities services.

The logic of the initiative in terms of outcomes

Defining self-determination in terms of these driving forces allows another sketch of the logic of the initiative. According to the proposals, implementing self-determination will lead to increased satisfaction for people with developmental disabilities and their families and to better use of available public funds.



There is a third outcome which most proposals imply or include in statements of principles without much additional discussion. Usually by implication, the proposals seem to assume that self-determination will also promote the realization of the values and vision the reformers who wrote them hold.



It isn't clear why so few proposals clearly state this outcome and recognize the tension it introduces as fundamental to the initiative. It may be that states or at least project areas have achieved such a very high level of common understanding of the operational meaning of the system's vision and values that it goes without saying. Reformers might assume that a sort of invisible hand will start work because their vision and values are so compelling that people and families seeking satisfac-

tion and economy will naturally make choices consistent with their values. They might be attempting a finesse by appealing to choice within fiscal limits as an unassailable value and counting on the future effectiveness of their control of the allocation process and their tactics for informing people and families about what is possible to persuade people with divergent visions and values. Or, maybe, my own understanding of the meaning of common words about vision and values creates an unreasonably narrow standard and the contradiction is confined to my own mind.

However that may be, this double or triple claim seems ambitious. How ambitious it is depends on at least three things:

- One's understanding of two phrases common in the proposals: the outcome, "Better use of available public funds" and the related assertion that the existing configuration of services is "too expensive."
- The extent of loyalty to existing service arrangements and the level of power available to those who want to defend them.
- The degree of agreement about the day to day implications of the system's vision and values among people with developmental disabilities, their families, service providers, and reformers as distinct from assent to fuzzier sentiments like "respect for rights". (Think of the number of ICF-MR owners happily unconflicted about declaring their facility a model of self-determination and inclusive community.)

Pursuit of these outcomes through the medium of self-determination generates several kinds of conflicts. In designing the approaches a pilot will use to negotiate these conflicts in a principled and creative way, it will help to anticipate the sources of some of the most likely of these conflicts.

Best use of public money

People involved in cost containment debates may differ in their sense of what "better use of public funds" means because they understand the statement that the existing system is "too expensive" differently.

If "too expensive" means that the developmental disabilities system ...	then "better use of public funds" means that self-determination will...
... contributes significantly to the long term care sector consuming too great a proportion of the GDP...	...reduce public expenditure on the developmental disabilities system and thus on the long term care sector overall.
...consumes too much in relation to other public expenditures...	...reduce overall demand on public dollars from people with developmental disabilities and their families.
...expends too much on average in relation to other groups who need long term support...	...bring developmental disabilities system expenditures per person in line with expenditures on supports to elders and people with other disabilities.
...pays too much per person for some people with developmental disabilities relative to their individual requirements for assistance...	...reallocate funds so that people get only what they need and pay for only what they get and use any surplus to serve people waiting

The first three understandings do not support the project's logic unless people with developmental disabilities and their families can be persuaded of the satisfactions of living with significantly less so that other groups or economic sectors can have a tiny bit more. People concerned with advancing the developmental disabilities system's agenda in debates about Medicaid reform may encounter people with one or another of these understandings. Those people are unlikely to be excited when they learn the sense in which the proposals generally view best use of available money.

Most people in the developmental disabilities system who are interested in self-determination understand these terms in the fourth way. The system's history of layering different funding programs puts some

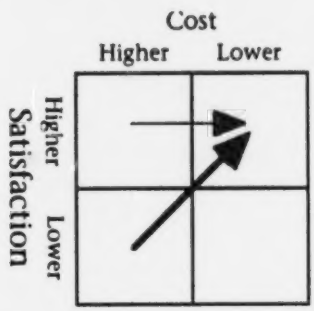
states in the position of paying very different amounts to serve people with similar needs for assistance depending on the funding stream in use at the time a person entered the system. For example, some people live in small ICF-MR programs that have grown costly when compared to services for people with similar or significantly greater needs who live in a supported living arrangement or a family care placement funded by an HCBS waiver or state general funds.

Loyalty as a threat to intended outcomes

The self-determination initiative will deliver both better use of public money and higher satisfaction only ...

...if people move from more costly alternatives which are less desirable to them to less costly alternatives which are more satisfactory, or

... if satisfied people find equally satisfactory supports at lower cost.



The proposals usually define people with developmental disabilities and their families as "consumers" and talk about "consumer satisfaction" as a primary measure of the success of the self-determination initiative. Proposals also make a strong and sensible argument for trusting people with developmental disabilities and their families to make their own decisions.

There could be a significant number of people with developmental disabilities or family members for whom "no change" is the most satisfying situation. From their point of view, if a high cost service is highly satisfactory, attempts to inform them about other options may seem intrusive, even threatening. They may see self-determination as a sell-out of what they take as a public responsibility to provide for eligible people. They may not recognize the people with developmental disabilities and family members who are members of project planning, steering, and advisory groups as their representatives in forming the consensus that the proposals confidently claim.

Conflict over who can decide as a threat to positive outcomes

Some family members, and some service providers, may disagree with service coordinator judgments about who can speak for him or her self and who needs the substituted judgment of a parent or guardian. In other situations, family and friends doing their best to put themselves in a person's shoes may surface remarkably different stories about what makes sense. In some states, a number of other people are under various forms of agency guardianship and sometimes, from the perspective of service coordinators and friends, guardians are distant and uninformed about the people on their caseloads and jealous of their prerogatives. It is interesting to wonder whether...

... a determined guardian could mount a successful legal or public challenge to the self-determination initiative as an unwarranted form of treatment.

...a determined service provider could successfully claim that liability protections or duty to offer care and protection trumps self-determination.

Self determination makes a fine framework for confronting these conflicts, but the proposals seem to underestimate the potential for conflicts -even intractable conflicts- over people's competency to decide.

Even when change doesn't challenge the terms of legal guardianship, it will take great skill to help a person assert their individual right to choose in a way that does not significantly decrease family satisfaction, at least in the short run.

At least one state gives people (and presumably their families) the choice to opt out of its local self-determination initiatives. The effects of this option, should many people take it up, would seem to undermine the logic of the proposal: what would keep people satisfied with high cost services from opting out and shrinking the surplus available? At least, this option modifies the sense that self-determination is a paramount value. One can determine that one will not be self-determining. Or, more problematically, one can determine that one's son or daughter will not be self-determining. It also raises interesting practical considerations for providers. Will they differentiate their offerings into services for people who choose not to be self-determining and supports for people who do? For a glimpse of the worst case of dealing with people opting out, think about states that have "respected family choice" -and given in to the power of families allied with some unions and some providers- and kept people institutionalized as costs for keeping up "a full continuum of options" have spiraled.

Dissatisfaction may also be stimulated by the perception that the self determination initiative is an administrative reform, originating from the state level. It may not look that way to activists who moved the initiative up the system, but it may well look that way on its way back down. This could create suspicion and resistance if local providers and consumers decide that self-determination is really a top-down effort to cloak a budget cut in rhetoric about freedom and responsibility. A similar problem may arise if the supporters of more controlling, segregated services view the project as an attempt by zealots to impose unwanted values. The resultant conflicts could escalate if reformers attempt to claim the moral high ground and create the paradox of reform minded professionals telling self-determined people and families what is good for them.

It will put a substantial burden on the initiative's leadership to keep these conflicts from spinning into a destructive cycle of misinterpretation and misrepresentation.

A few states seem to have invested significant effort in building agreements among many of the people who are stakeholders in the system. They may have easier going, at least in the early stages, than states with smaller numbers of people involved in their partnerships. These partnerships may be equally representative in terms of involved people's roles (consumer, parent, provider, community member, administrator, even legislator) but they may be thinner in terms of both numbers involved and diverse values worked through to common positions. In any event, it won't be surprising if local managers and local authority members find themselves spending a great deal of their time interpreting and reinterpreting the intent of the initiative to confused and threatened people. Their own conviction and clarity will be a key resource in assuring that conflicts are surfaced, confronted, and managed in a principled and creative way.

Loyalty as a resource

The logic of consumerism makes customer loyalty an important resource to service providers. Loyalty affects judgments. What may seem to reformers like the regulatory imposition of unnecessary clinical services may seem to a guardian/consumer like an entitlement, an essential contribution to their peace of mind, or an important relationship to maintain ("I really like seeing my speech therapist."). Service providers convinced of the benefits of their higher cost congregate services may market their services even more vigorously, differentiating their offerings on the basis of their specialization in the high vulnerability and arcane needs of the people they serve. Concerned providers

will look for ways to modify internal conditions in response to customer complaints and suggestions in order to increase satisfaction without having to change their pattern of service ("Resident satisfaction has increased significantly since we have let the self-advocacy committee set bedtimes."). Attempts to inform their satisfied customers about alternatives to what they provide may seem to them like biased attempts to rig what according to at least one account of the self-determination model should be an evolving market.

To keep these issues from miring the initiative it will be important for the responsible local authority to take a clear position about what sorts of alternatives are "off the menu". For example, does it fall within the boundaries of self-determination if...

...a family guardian wants to purchase a place in a village for the retarded in another state

... ten families propose pooling their individual budgets to set up a group home ...eight families ...four families

...a person wants to purchase a place in a local sheltered workshop outside the DD system

The question of what is off the menu is a thorny one. For instance, committed and progressive parent advocates hold very different views about whether parent choice is a higher or lower value than individualized supports. Change initiatives that proceed "one person at a time" can delay defining these boundaries. The self-determination initiative, as a system level change, cannot.

Loyalty is also a vital resource for the self determination initiative itself. When people with developmental disabilities and their families and friends identify somehow with other people with developmental disabilities, especially those who do not have services, they will have reason to find creative ways to cut the costs of their services. Within the individualistic frame often expressed in terms of a sense of individual consumer rights, it is harder to see the reason for taking any action except those directed at getting and protecting mine. This points to one of the most interesting contradictions that shapes the self-determination initiative: individual choice within the constraint of membership in a chronically under-resourced group.

Unless people develop informed loyalty to the self determination initiative, it will be hard for them to see rationing decisions as fair. This will be especially difficult because most accounts of self-determination demote the role of "objective" measurements of need in favor of negotiated budgets based on person centered plans. Unless people embrace a

complex notion of individualization, they will be tempted to compare budgets and question why someone else who seems to have the same condition as their son or daughter gets more.

The vocabulary of consumerism provides a shaky foundation for the kind of mutual-responsibility that seems necessary to the initiative's success. Building such mutuality will stretch everyone's creativity.

The logic of the marketplace

Many people find the idea of re-designing the system so that people with developmental disabilities are customers in a marketplace of services to be the most straightforward way to redress the power imbalances inherent in the existing system, to assure responsiveness to people's choices, and to promote the development of effective services. A number of accounts of self-determination invoke the logic of the marketplace as a trope which adds to its intelligibility and appeal.

However understandable and appealing the logic of an emergent marketplace may be, in the context of self-determination this metaphor raises as many questions as it answers.

- Self-determination is explicitly not an income transfer program. This seems to be less a matter of principle than an accommodation to probably valid assumptions about the endurance of the developmental disabilities system's dependence on Medicaid money and Medicaid's continued prohibition of cash payments. (In this sense, this RWJ initiative is betting that another RWJ initiative, "Cash and Counseling" will be unsuccessful in shaping long term care policy.) This means that people with developmental disabilities are only customers through the intermediation of an agency. While proposals are not detailed on this point, most seem to assume that the same agency could act as both a fiscal intermediary and the rationer of available funds.
- Some people think that market logic challenges individualized budgeting, at least insofar as it departs from the simple assignment of a certain sum of money based on a standardized and objective assessment of need. They argue that the market will be able to achieve far greater efficiencies if providers set a price for their service which consumers can either afford or not. If some can supplement this amount or if lower priced options are required, providers -not state or local bureaucrats- are best positioned to offer different kinds of services at different price points. Perhaps large hostels or SRO facilities modeled on successful services for homeless people might make

a good no-frills option for more able people whose allocations will thus be very limited. Poor people with greater needs for care could benefit from nursing home services which are relieved of the burden of offering "active treatment" and allowed to simply provide asylum. Perhaps other providers might find a way to gain an advantage by offering a bit more luxury at low cost (maybe in an alliance with the Motel 6 chain). From this point of view, individual budgeting looks like an attempt to impose a kind of command and control economy on the details of provider's work. This interferes with the provider's right to pursue whatever line of business the market will support.

- Some people say that market logic undercuts the case for local allocation mechanisms. The more standardized the method for assigning money and the larger the scale on which payments can be processed, the lower the transaction costs can be driven. To date, managed care companies have found efficiencies in growing bigger; not in multiplying boutique agencies around a state. Analysis of large numbers of cases will offer better allocation algorithms than having a number of amateur local boards fooling around with capitation rates for a few hundred people.
- Scale is an issue on the provider side as well. While some providers hold their scope within the boundaries of a local allocation authority, other providers have significantly improved their margins by growing bigger. More than one agency has decided that success lies more in the direction suggested by Walmart than in the operation of small, local agencies (to track this phenomenon see the occasional section in the *Community Services Reporter* entitled "Large Provider Watch"). How people and their intermediaries will find strategies to deal effectively with existing big providers and the trend to growing scale in provider agencies will be interesting to see. A commitment to develop small local providers and to find creative ways to induce people to "do it themselves" by developing quasi-agencies for one or two or three or providing "community utilities" to offer payroll services may make considerable sense on the grounds of quality, but market thinkers might question the logic or fairness of paying a premium for home grown services. Those who think that smaller scale can be cheaper might be right, but they will have to contend with arguments from analogy like these two, "If that's true, why are there so many MacDonald's and so few local diners?" or "Why should we subsidize some people's desire to buy organic carrots from the local community garden when others can't even afford carrots from factory farms at the discount megamarket." There are also hard questions about how much it actually costs to develop and maintain a small option. John Shea has documented 18 person months of unpaid

family effort required to initiate Options[3], which supports three people with developmental disabilities who choose to live together. Implementing the self-determination initiative would probably reduce this cost, but it isn't easy to estimate by how much.

Like nearly every American reform effort, persuasion around the self-determination initiative often casts self-determination as the clear and obvious way that values rooted in a sense of the collective past can be defended against modern excesses. In this case, self-determination rescues individual freedom and responsibility from mindless bureaucratic over-regulation and arrogant professionalism. Self determination promises a future that will renew past values, with renewed community responsibility arising from the defeat of professionalism as a bonus that shows up on the bottom line. This rhetorical device is so effective that even bureaucrats and professionals appeal to it. It does embody worthy hopes and so there is little reason to challenge it, as far as it goes. It goes up to the point of implementation. From there on, some time spent challenging the ahistorical assumption that self-determination is not just a new wrapper but a new order for the ages (to quote the dollar bill) may alert us to some obvious pitfalls.

One test I can think of off- hand would be to answer the question. "What are the real differences between the self-determination initiative and the California Regional Center system?" While there are obvious differences, such as the clear entitlement to services that Californian's enjoy, there are some instructive similarities: both rely on a modified market logic, an independent brokerage and purchasing system, and a requirement that service purchases reflect individual needs and preferences as defined by a plan (in fact, since last year, by a person-centered plan created with the assistance of a circle of support). Many of the differences seem to me to arise from differences in scale and duration rather than in concept, but that impression would benefit greatly from discussion. Of course, having the benefit of more than 20 years of California's experience to draw on should make a real difference in the way the self-determination initiative works out. That would be the point of the exercise.

Clarity about expanding service capacity

When promising results from a reform effort, it makes sense to be clear about what people might reasonably expect. While at least one state proposes explicitly to reserve savings during the project period to the use of the people within in its project groups, other proposals suggest that reducing the numbers of eligible people waiting for necessary supports is the best use of money saved through the self-determination initiative. This makes sense as an argument for retaining savings within the developmental disabilities system, but the proposals don't offer much analysis of the prospects for people actually moving off the waiting list.

None of the proposals sets a constraint on the individual budgeting process in the form of a number of people who will be moved from the wait list within the existing budget. Given the uncertainties involved, it makes good sense not to set a fixed rate of tax on individual budgets as implementation begins. Instead, some proposals only mention the general principle, while others specify desired or required savings (tax rate) -like 15% of current expenditure over three years- without indicating how this tax is to be allocated or how many people the proceeds might serve.

There are some parallels between this set reduction and proposals for taxing health care providers to extend the scope of available health care for uninsured people. Physicians and hospital corporation tend to resent and resist this sort of tax., which might lead one to question the equity of redistributing funds among the poorest people in our society, however consistent the practice may be with recent budget balancing tactics.

Calculating the number of people likely to move off the wait list seems to require estimates of the value of at least these ten fuzzy terms:

- The number of over-served people and the recoverable cash value of over-serving them. It is notoriously difficult to recover anywhere near the per-person cost when someone moves out of a congregate living arrangement that remains open. Some areas have already been quite rigorous in budgeting on an individual basis for several years; they may have less to show in the three years ahead than areas that maintain substantial investments in small, high cost congregate settings will. Local authority to control funds supporting people in state institutions (where they still exist) would probably create a healthier surplus; similar control over funds going to nursing homes would also help, though probably not as much.

- The number of people who identify reasonable substitutions for existing unnecessary and undesired services and the cost of those substitutions. For example, some people who have not benefited from the clinical services bundled with their ICF-MR placement might benefit significantly from more individually relevant and more intense services aimed, for example, at improving their communication or mobility. Others might make a strong case that higher than usual wages for a person's assistants would yield substantial benefits in continuity and competence. Ruling out such substitutions up front would substantially reduce the local authority's room for negotiating satisfactory deals with people who are initially reluctant to make a change. Allowing them raises interesting questions about the broker's loyalties in negotiating lower cost substitutions.
- The cash value of the reduction in paid support replaced by the person's own efforts, the person's efforts aided by technology, and volunteer labor from other people.
- The cash value of additional entitlements or benefits for which the person qualifies minus the cost of establishing or maintaining them.
- The cash value of gifts or subsidies or trusts from family members, friends, or community members minus the cost of raising or administering these benefits.
- The cash contribution the person makes to their support costs from wages plus the reduction in system expenditure allowed by the person's contribution to rent and living expenses.
- The cost of serving the next person from the waiting list, taking account of the values of each of the terms above for that person. (For the "cost of over-serving" and "substitutions" consider the costs of planned high cost/low satisfaction services, if any were contemplated).
- The amount of money it seems prudent to retain at the level of the locally responsible body in order to respond to changing individual needs and crises (some call this a "risk pool").
- The cost of restructuring existing administrative and service arrangements to support more satisfying/ lower cost services (some call this "investment in infrastructure").
- The number of providers of higher cost/ lower satisfaction services who discontinue those activities instead of finding ways to refill the vacancies left when someone moves on and the cost of closing existing services. This in turn depends on...

  ...the whole developmental disabilities system's capacity to manage demand for places without using higher cost/ lower satisfaction

options. For example, a state under pressure to move people from an institution may find it difficult to see a ready supply of established residential places disappear. From the local perspective, resisting "backfilling" existing slots with people from institutions and nursing homes may decrease the area's contribution to state objectives. Accepting such "backfilling" will bring in new money, but from the point of view of the whole system it represents little if any savings.

...the extent of regard for the financial interests of existing providers and the means available to protect them from loss of their fiscal investments in high cost/ low satisfaction options and assist them to deal with the costs of going out of business or making a transition to new forms of support.

Natural support: Solution -> problem

Many proposals mention "natural supports" as an untapped resource which can be substituted for at least some paid services. Leaving aside quibbles over definition -like whether help remains "natural" when the service system accounts it as a way to balance the books on a service plan- the appeal to "natural support" raises several issues.

Some of these are simply questions of having sufficient clarity about the expectations of families that are contained in references to "natural support" to anticipate likely conflicts and to avoid inadvertently visiting family members with one of their nightmares.

- In any state where significant numbers of adults with developmental disabilities with needs similar to those whose residential services are publicly funded live with family members, there is already considerable natural support saving the system money. To these families, the notion of helping your son or daughter out on a day to day basis won't be a new one. The offer of an opportunity to offer natural support may, however, seem to some people like a bait and switch maneuver on the part of a system with which they thought they had an understanding that "We'll look after him until the time comes, and then..."
- Some family members of people receiving 24 hour services will also sense a major shift in the contract they believed that they had with the service system. Some may believe that the system renewed their 24 hour contract in exchange for their consent to a move from an institution. Some may wonder how they are to contribute in a practical way to someone with whom they have had limited contact or someone who lives a long way off. The enforceability of any of these

family expectations is not at issue. What matters is finding ways to deal with disappointed expectations that align family resources behind the person with a developmental disability.

- Very often, "family" is short for "mother and dad" and often for just "mother." Sisters, and especially brothers, even when they live nearby, may not have thought much about offering day to day help as a substitute for paid services.
- There are significant estate planning questions around family contribution to people's support if that contribution is to continue in some form through the person's life.
- In several places, politically savvy parents have distanced themselves from equally sophisticated families who contribute money and effort to services because they see them as selling out to a system that has an obligation to provide services to eligible adults without cost to their families. Given the opportunity to substitute their efforts for those of the service system, some family members advocate for lower cost, congregate service options. Working through the politics of self-determination will be an important challenge for advocacy groups, especially in the context of the partnerships the proposals describe..

The experience of people who have grappled with these difficult issues suggests some lessons:

- It is more effective for parents (including parents who work as staff or managers) who are committed to a different kind of relationship with the service system to deal with other parents on these issues than to leave it to non-family members.
- With some families, it is extremely challenging to promote both the idea of increased family contribution and the idea of promoting the person's autonomy at the same time. To some, being directly involved means being in charge of what happens.
- Given the opportunity, a significant number of family members say no to the prospect of substituting their time and money for work that they believe belongs to the service system. In at least three places, this has been true even when the alternative was for a person to remain at home and on a waiting list.
- It takes substantial, continuing effort to keep the contribution of family members, friends, and service providers aligned. Plans take time and effort to negotiate. Agreements and understandings fall apart and need repair. Family member's capacity to substitute for service providers waxes and wanes.
- Not all people with developmental disabilities welcome the active involvement of family members in their day to day affairs. Many others can identify a downside to family involvement.

Of course, these lessons come from settings where self-determination is not a matter of policy and where the partnership with families has not (yet) extended to include the whole diversity of family views. Pilots need to design approaches that will maximize the positive difference the policy change and the partnerships make.

The other issues that arise from the proposal's focus on "natural supports" raise four uncertainties about the kind and extent of help that friends, neighbors, and other community members will provide. Experience clearly shows that a substantial number of people with disabilities can recruit other people to help them. It is not clear how much of this help is fungible with paid supports.

- Many people will help out in crisis; or when there is a specific goal to attain, such as finding and moving into a new house; or incidentally to some chosen shared activity, like helping someone eat while out for meal with them; or around a specific and limited task, like acting as a representative payee or helping a person screen prospective assistants. Many people will offer emotional support or advice or companionship while pursuing a common interest. Some will help people represent their interests or defend their rights when they are in difficulty. Clearly all of these kinds of help have a direct effect on the quality of a person's life. How much this substitutes for paid service remains uncertain.
  - Many people gain confidence and skills from their friends or from membership in a self-advocacy group or another community association. No doubt this reduces demand for some kinds of assistance.
  - A number of people have an "If I get in trouble I can call you." relationship with neighbors or friends which can satisfy individual concerns about security when a person stays alone.
  - Some people with developmental disabilities who choose to live together provide considerable help to one another.
- Sustaining these kinds of help from friends is itself work. Often this work is done by paid staff either as part of a project, like many of those focused on circles of support, or it is done incidentally to another role, such as service coordination. Friends and community members often seem most comfortable contributing along side a staff person. There are many advantages to this kind of collaboration, but it is far from a no-cost activity.
- While there are many encouraging examples of co-workers and employers helping people succeed at work, and a number of people have found benefactors in their daily round of neighborhood life,

there are many fewer examples of friends and neighbors providing day to day assistance in a way that would reliably substitute for paid assistance to people with significant needs for personal assistance.

  - There is a wide variety of what might be called "discount help" relationships, in which some money or other consideration, such as reduced rent, buys significantly more help than it otherwise might because of the role the assistant takes or the relationship the assistant feels to the person. Many family care or foster sponsorship relationships have this quality.
  - Paid staff or, less frequently, former staff, may offer people more assistance than they are paid for and different kinds of assistance than they are paid for. This may happen as part of a friendship that includes other shared activities; occasionally, it is mostly an instrumental matter.
  - Each of these forms of unpaid help could raise issues around compliance with increasingly Byzantine labor laws.

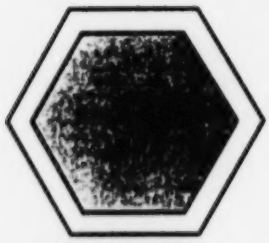
- Approaches to organizing help from friends are far from an effective technology. Some people show obvious gifts in bringing people together in a focused way; others use the same methods with little practical effect. Even gifted connectors have a difficult time helping people who have been cut off from family and isolated to recruit helpers who will sustain the relationship without considerable support from the connector.

All of these questions and uncertainties make the case for the self-determination initiative to focus on "natural support". But if others' experience is a guide, it is important not to underestimate the amount of learning that remains to be done or overestimate how soon support from friends and community members will have a significant impact on the bottom line of individual budgets or how big or sustained that impact will be.

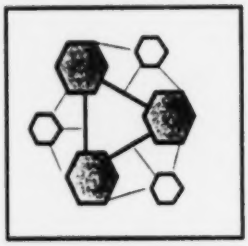
Changes and methods

Overall project design

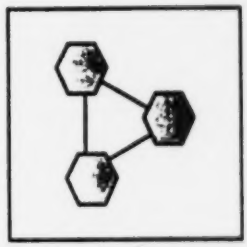
There is are interesting contrasts among the proposals. Considering these differences may extend the repertoire of each project. Here are three different ways states have structured their initiatives.



One layer of ongoing whole system redesign



Project areas plus network



Project areas

One proposal aims to complement other activities in an ongoing restructuring of its whole state system. The other proposals adopt the approach of piloting self determination projects in three or two places and then disseminating the change through the system. Usually these areas are coterminous with authorities established in state law or state agency structure, though sometimes the proposal targets a sub-group of people within the pilot area. Reflecting the timeliness of the initiative, a number of proposals recognize a second tier of areas with strong interest in the project as part of a network linked to the project.

Projects vary in their interpretation of RJW's expectations for the project.

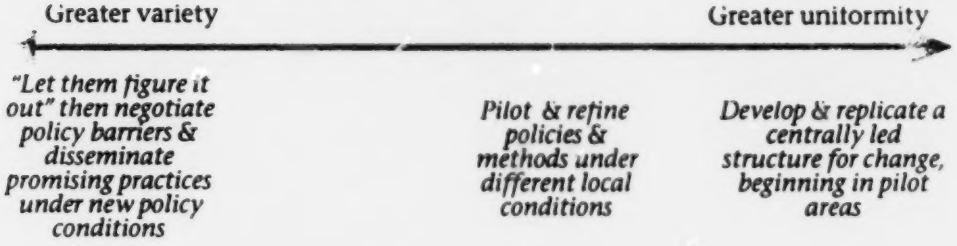
Self-determination as a theme; projects invent policies, structures, & methods

Self-determination as a model; projects replicate established policies and structures at test the effects of different settings to refine and extend the model.

Some projects designed their proposal more as though RWJ was proposing a theme for them to explore by inventing strategies, policies, and approaches that would extend understanding of what self-determination means. Others designed proposals more as though the foundation expected them to replicate structures and procedures developed in the

New Hampshire project previously funded by RWJ. Informal conversation with a few of the teams who received site visits suggests that the site visit seemed have the purpose of moving them to the right, toward the replication end of the scale. Both state and pilot areas need to negotiate clarification of the Foundation's expectations as soon as possible. If their purpose is replication, it is hard to imagine a reasonable evaluation without careful specification of the structures and procedures that are to be tested. If the Foundation has a looser understanding of replication, its edges need to be clear.

Each proposal establishes a statewide structure to support the projects, deal with state level barriers to project success, and focus and disseminate what project sites are learning. Proposals vary in their expectations of uniformity across project areas from supporting sites with quite diverse structures and agendas to each define and take their own next steps through sites piloting and refining methods and policies to be applied across the system to the systematic roll-out of a cooperatively defined but centrally led process.


Greater variety
Greater uniformity
"Let them figure it out" then negotiate policy barriers & disseminate promising practices under new policy conditions
Pilot & refine policies & methods under different local conditions
Develop & replicate a centrally led structure for change, beginning in pilot areas

Proposals that opt for greater variety reflect administratively decentralized state structures. Toward this end of the spectrum, self-determination will come to mean what each area makes of it. Their approach allows wide experimentation and creates a dissemination puzzle: how and in what form will the lessons and methods created in one area find their way throughout the rest of the system. Other proposals focus more on crafting the administrative policies and mechanisms that will stimulate self-determination in local systems. Proposals that choose greater uniformity bet that there are already known, reliable ways to implement self-determination and that the problems they face are teaching people how and resolving technical problems. Ready to implement self-determination may bring different results than the variety that requires local discovery. It will be worth trying to discover and describe these differences clearly.

The proposals reflect a wonderful array of state and local initiatives designed to support families, support people in their own homes, support people in jobs, plan with people in ways that take account of their personal identity and strengths, build circles of support with people, and promote constructive community engagement with people with developmental disabilities. These myriad initiatives typically include strong attempts to increase people's autonomy and control and many of them have better use of funds and multiplication of resources as part of their rationale.

The self-determination initiative provides a way to consolidate and extend the gains from these projects, and the pieces are sufficiently complementary to make the result look more like a mosaic than a collage of odds and ends.

Most proposal writers have heard a lot about "managed care" and most add more than a dash of it to their recipe for self-determination. In some proposals, "managed care" plays a role rather like that of the Green Knight in Sir Gawane's tale. This terrible figure upsets Gawane in combat, claims his life, makes him a cruelly impossible bargain as the price of his freedom, puts irresistible temptation in his path, and, at the mortal moment, becomes the way to greater purity for Gawane and the other knights of the Round Table. (If Gawane and the Green Knight is too remote, think of Luke Skywalker and Darth Vader, though neither the story nor the parallels are quite as good.) Thus, "managed care" is, at different moments in the proposals, a great threat which has already overcome us, an irresistible temptation, and the source of the exact tools we need to move our system along the path to higher levels of efficiency and effectiveness (which is what passes for virtue in the narratives of public management). If we use these tools skillfully we can escape "bad managed care" and enjoy "good managed care".

It is surely far better to jump into the managed care affray and vigorously wield our concepts of how it ought to work than to wait and see if reformers with other interests take good care of us. But I think we are too close to the beginning of the adventure to make much of a judgment on how these tools will work. Maybe they will slay the dragons; maybe we will cut our fingers. This initiative will help us find out, especially if it helps us defend against being overtaken by less subtle Medicaid reforms. Amid all this uncertainty one thing seems pretty sure: calling a mixed bag of untested policy notions "tools" stretches the usual sense of that word quite a bit. The defining feature of the tools I know is reliability at producing a result: nails driven straight, machine

parts milled to .001 tolerances. Identifying, for instance, "service substitution" a "tool" dignifies this untried notion with more reliability and engineering cachet than it has yet earned. This may be OK if it keeps us in the Medicaid reform game, but we have to stay vigilant so that we don't get mesmerized by our own metaphors.

How big a change is the move to self-determination?

Many proposals define necessary changes in a straightforward way. Though there are references to paradigm shifts, these tend to be perfunctory. When describing the work and its intended results the task is usually presented as linear: win the flexibility to do more and better what we already know how to do. We have the tools to do the job if RWJ gives us the money to do the necessary organizational work. This understanding of the needed change might be abstracted like this:

> *We know what we need to know to make self-determination happen. There are two primary sorts of barriers: 1) administrative problems which call for revised policies and procedures, implementation of new structures for allocating and tracking funds on an individual basis, and restructuring quality assurance mechanisms; 2) predictable resistance to change by provider organizations and their staff, which mostly comes from insufficient understanding of the principles of self determination, lack of skills to implement self-determination, and lack of information and procedures for redefining personal and organizational roles. These barriers can be overcome by problem solving and negotiation with funding authorities and policy makers through proposals developed with the aid of expert consultants and by training and technical assistance about how to implement self-determination, most of which we already have the curriculum and materials to deliver. Our greatest uncertainties concern: 1) the degree of flexibility we can negotiate with Medicaid; and 2) how to set capitation rates and make allocations in a fair, effective, and efficient manner.*

Some proposals embrace a higher level of ignorance and uncertainty. They identify the need to create new strategies for engaging community members in the lives of people with developmental disabilities. They call for a process of discovery. For example, some propose imitating the earlier New Hampshire project by using a method that might be called reasonable arbitrariness to set their notional budget limit (which some proposals confusingly call a "capitation rate"), jump into the individual allocation process, and make adjustments as reflection on

experience provides new learning. Others propose using some consultants as facilitators of local agenda setting, action planning, and learning rather than as technical experts who will install appropriate policies or procedures or concepts.

Some proposals recognize that the politics self-determination can extend beyond the administrative boundaries of the service system. They propose to use project resources to strengthen the organized collective power of people with developmental disabilities and their families so that currently better organized providers and bureaucrats feel organized countervailing forces. They want to find ways to mobilize community members not just as helpers to individuals but as owners of a share of necessary system changes.

Overall, the proposals are optimistic about the prospects for substantial change with a relatively modest investment for coordination, technical assistance and training. This is clearly good proposal writing, but it might leave people with developmental disabilities with a more shallow experience of self-determination than would be necessary if the projects gather the strength to push the process of change deeper.

I share the proposal writers' confidence in our ability to shift the mechanisms that flow money around individuals. Real political problems will arise as things move from promises in a proposal to real change in the money flow and opponents within and outside the developmental disabilities system wake up. So there is a chance of defeat when opponents mobilize and the bureaucratic gum begins its sticky flow, but, given the times and the support that proposals have already generated, I will bet on us reformers to win more flexible individual allocations in the end. Uncertainties in timing may matter, though: if it takes six months to unstick a procedural issue around money flow or three months to get agreement with external inspectors about how new supports relate to licensing regulations, or if it takes an extra six weeks to implement the software package the technical assistant developed to track individual budget, the project's momentum may suffer badly. There are knotty technical problems in designing fair, efficient, and effective methods for making decisions about money at the state, local, and individual level, but our efforts will benefit from consultation by a number of smart people who are committed to increasing the control people have of their lives. I will cheerfully bet on the effectiveness of technical assistance in developing the next steps forward. My bet is secured by two characteristics of this aspect of the change: it is about money that the system controls; and, the decision rules and procedures that technical assistants help us design can be tested and improved in a linear way.

The areas in which the bets seem worth making, but much riskier, are, curiously, those that many proposals take almost for granted. They are usually presented as objectives, thus categorizing them as "results we know how to achieve" (or so it looks from the way the Gantt charts are constructed). While I think it is possible and very important to make real progress on these issues, I think that most of the proposals significantly underestimate the depth of learning required to...

- transform the architecture, position, and processes of provider agencies; this has been difficult even when agencies start fresh around a mission of individual and family support, but it has proven extremely difficult to transform an agency that has made a real success of controlling people with developmental disabilities
- redefine the loyalties, roles, and functions staff enact in people's lives
- make the transition from case management to service coordination
- assist people to gather and sustain support from family and friends and especially to extend their personal resource networks
- find creative ways to help people address the depth of their material poverty
- confront the conflicts that this shift will surface in a way that makes the principles of self-determination the stimulus for creative resolutions
- work and plan with people in ways that support the emergence of their identity as real contributors to community life
- hold together people's personal assistance systems over time in ways that honor people's autonomy and choice
- find satisfying connections to the people and associations in communities so diverse and confusing that the very idea of community slips in and out of focus.
- facilitating leaders with developmental disabilities as they develop powerful organizations

In these areas, I believe that "training", "curriculum", and "technical assistance" are very limiting metaphors for what we have to change. We will need to explore more complex ideas about change and we will have to push our exploration well beyond consultant-babble about "chaos theory" or "transformational leadership" or "generative learning organizations" or "principle centered leadership." Each of these sets of notions, and many others, may contribute, but only if people stay serious about the radical nature of the task.

Service coordinators as a key limiting resource

Some strategic thinkers hold that every enterprise has at least one key limiting resource, something other than money that will act as a brake on increasing effectiveness. This kind of analysis can help temper the optimism necessary to build momentum for change as self-determination projects move toward implementation. There may well be more than one key limiting resource. Certainly the supply of flexible and creative leadership among providers is a good candidate. So is the supply of honest and capable personal assistants who will hang in with people through time. To illustrate this point of view on implementation, consider the case for the service coordinator as a key limiting resource.

The rules of the exercise say that the key limiting resource has to be something other than money. Proposals put considerable emphasis on the movement and control of money, while they quietly accumulate vital tasks for service coordinators to either do or assure get done -and most anyone who has actually done the work says that doing is hard but assuring is really hard . At least for people with disabilities who are not unusually gifted in making their lives work or possessed of talented, energetic, and skilled family, friends, and personal assistants -in short, those who can make almost any system work for themselves- service coordinators are one key limiting resource.

Service coordinators are not the whole show, but they do have an important contribution to make to...

...the alignment of family members, friends, and personal assistants around the person's non-negotiable present and desirable future

...the creativity with which support plans replace higher cost/lower satisfaction services with effective/lower cost support

...the degree to which conflicts are contained and resolved in principled ways among involved people close to the person

...people's sense that the allocation process has treated them fairly

...the cost of making adjustments to people's support arrangements

...the standards that people hold one another to around the principles of self-determination

The very point of the self-determination initiative is that people with disabilities and their family and friends can take responsibility for these kinds of problem solving. But many will need more support than they can get from a training workshop on self-determination, no matter how good it is or how eloquent the process diagrams may be. Staff who know and care about a person they assist have deep untapped wells of creative

action. But many staff need help sorting out how they can best contribute, at least from time to time. Community members may join in, but many of them will appreciate someone to support their contribution. The service coordinator's job calls for both ability to do these things and the judgment to make room for others to do them whenever this is possible.

Those of us who have watched service reformers pin their hopes on previous variations on the service coordination theme may want to think carefully about what has led to so much disappointment -not with the usually admirable people who do the job, but with the result of the forces that often defeat their ability to contribute. Such thoughtfulness would make us look for more than short courses and bits of technical assistance to support their development.

Maybe the depth of success achieved by the self-determination initiative depends on the local supply of people so crazy about the significance of people directing their own lives as they take a valued place their communities that they will challenge themselves and all those around them to discover new ways for people to live together and support each other. If so, the good news is that many such people seem to be available when good opportunities are there for them. Whether there are enough such people and whether their jobs will evolve in ways that sustain their focus and commitment is one of the many things the self-determination project will give us a chance to learn about.